Death certification after a diagnosis of presenile dementia

A J Newens, D P Forster, D W K Kay

Abstract
Study Objectives—To assess the value of death certification for the epidemiological study of dementia, the frequency with which the condition was recorded on death certificates of patients diagnosed with some form of dementia before the age of 65 years was studied. A further objective was to identify variables associated with failure to record dementia on the certificate.

Design—A cohort of patients with presenile dementia, differentiated by a clinical algorithm applied to hospital case records, was traced through the National Health Service Central Registry and details of certified causes of death were obtained.

Setting—The Northern Regional Health Authority in England.

Subjects—Prevalent cases of presenile dementia resident in the northern health region during 1986 traced up to April 1992.

Measurements and main results—the underlying cause of death was recorded as dementia or as Alzheimer's disease in 53% of cases of clinically diagnosed presenile Alzheimer's disease, 33% of cases of presenile vascular dementia, and 10% of cases of presenile dementia secondary to another neurological condition. Dementia or Alzheimer's disease was recorded in any part of the certificate in 75% of cases of Alzheimer's disease, 52% of vascular dementia, 33% of other dementias, and in 65% of cases overall. Dementia or a cerebral condition of a kind that can result in dementia was recorded in 80% of all cases. Failure to mention dementia was related to the clinical type of dementia, shorter duration of illness, and earlier period of study.

Conclusions—The underlying cause of death seriously understates the frequency of dementia, but when the recording of other brain disease is taken into account the presence of potentially dementing brain disease is recorded much more frequently. It is suggested that coding chronic conditions present at death, such as dementia, in addition to those causing or contributing to death would improve the value of death certificates for epidemiological purposes.

Methods
Patients with dementia or conditions likely to be associated with dementia (with the exception of Huntington's disease) were identified from the diagnostic International Classification of Diseases (ICD)-9 codes forming part of the Hospital Activity Analysis, Mental Health Enquiry, or Körner information systems from general and psychiatric hospitals. In addition, enquiries about cases of dementia were addressed to all day hospitals, social services departments, community psychiatric nurses, private nursing homes, clinical

Department of Epidemiology and Public Health, The Medical School, University of Newcastle upon Tyne, Newcastle upon Tyne NE2 4HH.

A J Newens

D P Forster

MRC Neurochemical Pathology Unit, Newcastle General Hospital, Newcastle upon Tyne NE4 6BE.

D W K Kay

Correspondence to:
Dr D P Forster

Accepted for publication
February 1993
psychologists, and selected general practitioner practices and records of neuroradiology centres were also examined.  

Period prevalence cases of presenile dementia during the calendar year 1986 in the northern health region were identified through contact with the above services between years 1980 and 1989 inclusive. The study was restricted to patients aged between 40 and 64 years (inclusive) whose illness was diagnosed by specialist hospital services. Every case was found to have been in contact with hospital services and it was therefore possible to apply the same algorithm to case note information in order to exclude cases in whom the diagnosis of dementia was not confirmed, remove miscoded cases, and to differentiate between presenile dementia of Alzheimer’s type (PDAT), presenile vascular dementia (PVD), and other secondary dementias.  

PDAT and PVD were distinguished from one another by the clinical algorithm which took account of the type of onset and course of the disease as well as a calculation of the Hachinski ischaemia score.  

Our criteria for PVD did not require the presence of multiple infarctions and this category may have included some cases with mixed pathology. Diagnosis of secondary dementia was based solely on the clinical diagnosis as recorded in the case notes.

Patients in whom a diagnosis of dementia was confirmed by case note study were traced through the National Health Service Central Register (NHSCR) which provided a copy of the death draft entry in the register of deaths showing the underlying cause of death as reported in mortality statistics, other details of diseases contributing to death, the date of death, and whether an autopsy had been performed.  

Monitoring of death continues and deaths notified up to April 1992 are reported here.  

The Office of Population Censuses and Surveys (OPCS) selects a single underlying cause of death based upon guidelines given in the ICD, modified by World Health Organisation rule three; and this provides the official mortality statistics. The underlying causes of death and also the immediate causes of death (cause Ia) were grouped into broad categories; Alzheimer’s disease, dementia, cerebrovascular disease, cardiovascular disease, other cerebral disease, and other causes.

To take into account all the information recorded in parts I or II of the death certificate, a classification was constructed to identify separately cases with dementia, cases with central nervous system or cerebral disease, and cases without mention of either of these conditions. For this purpose clinical cases of dementia were classified as follows:

<table>
<thead>
<tr>
<th>Table 1: Cross tabulation of clinical algorithm diagnosis of dementia and underlying cause of death</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Death certificate (Underlying cause of death (OPCS))</strong></td>
</tr>
<tr>
<td>Clinical diagnosis</td>
</tr>
<tr>
<td>PDAT</td>
</tr>
<tr>
<td>PVD</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

*Senile dementia, presenile dementia, and dementia.  
When PVD and other clinical diagnosis combined $\chi^2=22.6$ DF=5 p<0.01  
PDAT-presenile dementia of Alzheimer’s type; PVD-presenile vascular dementia.
as PDAT by clinical algorithm, 53% were due to Alzheimer's disease or dementia and a further 16% to a cerebrovascular condition. Of cases of PVD, 33% were due to Alzheimer’s disease or dementia and 26% to cerebrovascular disease. Of the other causes of dementia, 10% were coded as Alzheimer’s disease or dementia, 10% as cerebrovascular disease, and 30% as another central nervous system disease. There was a significant difference between PDAT and all other types of dementia in the underlying cause ($\chi^2=22.6$, DF=5, p<0.01) because of a higher percentage with Alzheimer’s disease or dementia in patients with PDAT.

**Time trends**

The recording of dementia increased significantly over the study period ($\chi^2=9.4$, DF=2, p<0.02) from 54% in 1986-7, to 68% in 1988-9, and 76% in 1990 and later. The increase for PVD alone did not reach a level of statistical significance ($\chi^2=2.9$, DF=2, p>0.05) but for PVD the increase was significant ($\chi^2=7.5$, DF=2, p<0.05). In this group, reporting of dementia or Alzheimer’s disease’s increase from 33% in 1986-7, to 57% in 1988-9, and to 81% in 1990-2.

**Duration of disease (onset of symptoms to death)**

In patients in whom the duration of disease was less than five years, dementia was reported less often (47%) than for those with a longer disease period (73%); this difference was highly significant ($\chi^2=15.6$, DF=2, p<0.01). This finding was not explained by clinical diagnosis.

**Place of death**

There was no significant difference in the recording of dementia or Alzheimer’s disease in hospital deaths compared with those in the community. A total of 171 cases (66%) died in hospital, 53 (21%) at home and 33 (13%) in a residential or nursing home. The percentage of deaths that occurred in nursing or residential homes increased during 1986-92 (6% in 1986-7, 9% in 1988-9, and 16% in 1990 and later).

**Discussion**

The relationship between the information given on death certificates and the diagnosis during life can be regarded from two points of view. The death certificate may be used to confirm or otherwise the correctness of the clinical diagnosis, particularly when a necropsy has been performed; however, to establish the cause of dementia this would have to include histopathological examination of the brain. In this sample necropsy was undertaken in only 10% and in none was histology available.

Alternatively, death certificates may be used as a source of information about the presence of a particular disease or condition in a population;
for instance to study regional differences in dementia.\textsuperscript{12} In addition, a reference to dementia on the certificate would suggest that the patient had been chronically disabled and dependent.

\textbf{VALIDITY OF DIAGNOSIS}

The general validity of the method of establishing the clinical diagnosis from case note review is supported by the calculation that in an unselected population of similar size and matched for sex and age at death, only one case of a dementing illness recorded as the underlying cause on the death certificate would be expected\textsuperscript{10} whereas in our group 113 (42\%) of these cases were observed. It would be wrong to assume that the remaining cases were not demented since 22\% died from the effects of cerebral or cerebrovascular disease, and in a further 14\% dementia or cerebral disease was mentioned on the certificate though not as the underlying cause of death. Some 80\% of all patients and 83\% of PDAT patients had some form of cerebral disease referred to on the certificate, which is a reasonable validation of clinical diagnosis.

There was a potential conflict between the algorithm diagnosis and the recorded causes of death in some cases. For example, of the 173 cases of PDAT cerebrovascular dementia was referred to in 18 (10\%) cases and in a further 19 (11\%) cases a cerebral disease other than Alzheimer's disease was recorded; cerebrovascular disease (11) Parkinson's disease (four), cerebral atrophy (two), epilepsy (one) cerebellar araxia (one), (columns 3 and 4 table II). Of all 84 cases of secondary dementia (PVD and other dementias), Alzheimer's disease was mentioned on the certificate in only nine (11\%) cases (table II). It is known, however, that clinical diagnosis of type of dementia does not agree perfectly with histology.\textsuperscript{11,12}

\textbf{THE DEATH CERTIFICATE AS A SOURCE OF INFORMATION IN POPULATION STUDIES}

The cause of death is usually recorded as the underlying cause, defined under article 23 of the World Health Organisation constitution,\textsuperscript{13} as "the disease or injury which initiated the train of events leading directly to death". The ratio between the frequency with which a disease is mentioned on the death certificate and reported as the underlying cause of death varies greatly with the nature of the disease. For example, for acute myocardial infarction the ratio is 1·06 whereas for heart failure it is 19·7.\textsuperscript{10} Therefore the underlying cause of death (on which the national mortality statistics in England and Wales are based) will accurately reflect mainly the incidence of acute conditions in which the case fatality rate is consistently high, but less so in chronic conditions. In the case of dementia, a chronic syndrome associated with varying frequency and severity with certain neurological diseases and, as age advances, with many co-morbid disorders, its contribution to death will vary and may be difficult to assess in the individual case. Hence in some cases dementia, though present, will be adjudged not to have contributed to death or else will be recorded in part II of the death certificate as contributory but unrelated to events leading to death. In this series, dementia was most often cited in this part of the certificate (table III).

Except for the ad hoc study referring to the years 1985-6,\textsuperscript{6,10} the frequency with which dementia is noted at any point on the death certificate is not available in England and Wales. In the US, in a national study, Chandra \textit{et al}\textsuperscript{14} found that age adjusted rates of dementia (senile and presenile) were about five times higher for death with any mention of these conditions than for death from these conditions when listed as the underlying cause.

In this study Alzheimer's disease or dementia was recorded as the immediate cause of death in 12\% of PDAT cases (table III). This is much higher than the 1\% reported as the primary (sic) cause of death in a study of older patients with Alzheimer's disease,\textsuperscript{3} and may be related to the better general health of younger patients, though the meaning of the term primary in not quite clear. As in clinical studies of older patients,\textsuperscript{2,3,15-17} the commonest immediate cause of death was bronchitis/bronchopneumonia.

In this study Alzheimer's disease or dementia was the underlying cause of death in 44\% of cases compared with 22\% in the study of older patients by Martyn and Pippard.\textsuperscript{1} However, the rules for determining the underlying cause of death changed during the course of the latter study (1981-6), which may account for some of this difference. Unlike this earlier study, reporting of dementia was not related to place of death (hospital or community). Dementia or Alzheimer's disease was the commonest underlying cause of death in PDAT whereas in other clinical types of dementia death was relatively more often caused by cerebrovascular disease, other cerebral disease, or systemic disease. In just over half of cases in whom the underlying cause of death was a non-cerebral cause, dementia or Alzheimer's disease was mentioned on the certificate.

In this sample, dementia or Alzheimer's disease was mentioned on any part of the death certificate in 65\%, about as often as reported by Martyn and Pippard\textsuperscript{2} (57\%), but in PDAT patients the rate was higher and similar to the 70\% reported by Burns \textit{et al}\textsuperscript{18} in older patients with Alzheimer's disease, most of whom died in hospital after a long illness. In the present study the rate of reporting in the 109 cases of PDAT who died in hospital was 79\%. It cannot be assumed that the failure to mention dementia in about one quarter of the cases was due to incomplete or careless certification since dementia may not have contributed to death in these cases. This is compatible with the finding that dementia was referred to less often when the duration from onset of symptoms had been less than five years than when it had been longer since dementia would have been less advanced and less likely to contribute to death from other causes.

\textbf{THE NON-REPORTING OF DEMENTIA}

Failure to mention dementia or Alzheimer's disease on death certificates was found in univariate analyses, to be associated with: type of dementia (PVD or other dementias as opposed to PDAT), male sex, younger age, shorter duration of illness, and earlier years of study. If cerebrovascular disease is combined with dementia as a cause of death, the difference between PDAT and PVD is reduced and the sex difference disappears. This
Death certification after a diagnosis of presenile dementia

procedure gives a better indication of how often the presence of cerebral disease is noted on the death certificate in the two main causes of dementia.

The increased frequency with which dementia or Alzheimer’s disease are reported on the death certificates of presenile dementia cases over the past six years is perhaps the result of publicity. Although a greater proportion of patients were dying in residential homes rather than in their own home or in hospital in the later years of the study, this did not affect certification. The finding that dementia or Alzheimer’s disease was mentioned more often in patients after the age of 65 than in those dying younger is somewhat surprising and may be due to chance since the difference was only of borderline significance.

DEATH CERTIFICATION AND EPIDEMIOLOGICAL RESEARCH

Martyn and Pippard and Jorm et al pointed out that the use of the underlying cause of death as reported in mortality statistics would be an economical way of investigating regional differences in the incidence of dementia; unfortunately the underlying cause of death was an unreliable source of information about the presence of dementia. The coding of all conditions mentioned on death certificates and their availability for research purposes (as happens in Scotland) would improve the value of death certification. However, given the present limiting criteria for reporting conditions on the certificate, the incidence of chronic conditions like dementia would still be underestimated. The addition of a section for chronic conditions present but not necessarily contributing to death would improve the value of death certificates as a source of information about the frequency of disabling conditions such as dementia likely to have caused dependency before death. Such a proposal would probably need international agreement but nevertheless is one that justifies serious consideration, particularly at a time when health need assessment of chronic conditions assumes such importance in purchasing health care.

We are very grateful to the Northern Regional Health Authority and the Medical Research Council for funding; to Mr Angus McNay and the statistics section of the NRHA and to the NHSCR at Southport for help with information.